

**Rehabilitative Input and Support Received by Older Adults
following a Mild Traumatic Brain Injury event.**

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Degree of Master of Arts in Psychology

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Abstract

Introduction: Older adults have been shown to be particularly vulnerable to the effects of mild traumatic brain injury (mTBI). However, limited research exists that examines the information and support received by older adults after a TBI, despite suggestions that input may be insufficient. We therefore aimed to evaluate the information and rehabilitative support received by individuals after mTBI, and to determine whether there were any age-related differences. *Method:* Adults ($n = 250$) who presented at the Christchurch Hospital Emergency Department over a 12 month period, with a diagnosis of mTBI were invited to participate in the study. Of these, 106 consented and 80 were able to be contacted for follow up. Participants were aged 18-85 years ($M = 48$) and evenly distributed into four age groups (18-30, 31-50, 51-65 and 66-85 years). Participants were interviewed over the phone using a questionnaire developed in a pilot study. Questions focussed on information and treatment received after the participants' injury, as well as questions about cognitive and mood problems following the injury. Data was analysed both quantitatively and qualitatively. *Results:* There were no significant differences between age groups for the number of post-TBI symptoms reported by participants. However, as predicted, the post-injury information and assistance received were inconsistent and differed across groups: 25% of all participants did not receive any information after their TBI, and older adults were the least satisfied with the information received. Post-injury assistance was most commonly offered by friends, family and significant others, but this may not have been sufficient to encourage complete recovery. Participants made suggestions for assistance and support that they would have liked following their injury. *Conclusions:* The current study has significant implications for the treatment of mTBI as ill-informed and neglected patients are unlikely to return to pre-injury functioning and mental state. Furthermore, a rapidly increasing older population makes immediate attention to mTBI in older adults imperative.

1. General Introduction

1.1 Overview

Traumatic brain injury (TBI) is defined as a traumatically-induced injury that contributes to the physiological disruption of brain function (Leibson et al., 2011) and is a leading cause of death and disability across all ages. It is estimated that between 200 and 558 individuals per 100,000 will experience a TBI (Feigin et al., 2013), but actual incidence of TBI may be higher than this estimate. While 95% of all TBI cases in New Zealand are classified as mild (Feigin et al., 2013), there is increasing evidence that even this level of severity can result in significant long term deficits and cognitive problems (Dean & Sterr, 2013). Evidence suggests that older adults may be particularly vulnerable to the effects of mild TBI (mTBI) and this population may experience poorer outcomes compared to young and middle aged adults (Rapoport & Feinstein, 2000; Rothweiler, Temkin, & Dikmen, 1998; Thompson, McCormick, & Kagan, 2006). This study will examine the information and rehabilitative support/assistance received by older adults following a TBI. With improvements in health care and the aging of ‘baby boomers,’ the population of older people in first world countries is rapidly increasing. Therefore any injury events that are common in this older population and that require medical resources represent a major medical problem.

The treatment of TBI requires significant financial input and is associated with substantial economic costs. For example, the most common mechanism of injury for TBI is falls, and Stevens, Corso, Finkelstein, and Miller (2006) found direct medical costs for non-fatal fall related injuries in the US to total \$19 billion. In their study, TBI accounted for almost half of fatal falls and associated costs. These costs are particularly relevant for older adults, as falls account for over 60% of mTBI cases in individuals ages older than 75 years, compared to only 10% of TBI cases in those 25-54 years old (Goldstein & Levin, 2001). Additionally, length of stay in acute rehabilitative facilities has been found to be an average of five days

longer for older patients and total rehabilitation charges are significantly higher for older adults as a result (Frankel et al., 2006). Older adults are also more likely than younger adults to require extended medical care after TBI (Dams-O'Connor et al., 2013). Given the greater frequency with which older adults (> 50 years) experience TBI and the poorer outcomes experienced there is an urgent need for further study regarding TBI in this population. This research may be useful in minimizing both social and societal costs.

Given the number of individuals affected by TBI, any ongoing problems are likely to have major health implications both in terms of direct and personal costs. The following literature review will examine reported outcomes associated with mTBI in older adults, as well as rehabilitation and support that is currently offered for this age group. The review will also identify current gaps in the literature and examine areas for improvement. This review is limited to research examining mTBI in adults, focussing mostly on older adults, but also included studies where a range of injury severities and ages were examined.

1.2 Injury classification

Severity of injury

Functional status following a TBI is a robust indicator of recovery from injury and although it varies between individuals, it can be predicted by a number of factors. For example, accurate predictions about recovery outcomes can be made based on the severity of the injury. One measure of severity is the Glasgow Coma Scale (GCS). Injury severity for this measure is assessed on three factors (eye opening, motor responsiveness and verbal responsiveness) and scores range between 3 (totally unresponsive) to 15 (fully responsive) (Namiki, Yamazaki, Funabiki, & Hori, 2011). An injury is determined to be severe when the GCS score is 3-8, and moderate when the GCS score is 9-12. A GCS score of 13-15 is classed as a mild TBI, where patients experience a loss of consciousness of about 20 minutes

and a hospital stay of less than 48 hours (Ramos-Zuniga et al., 2013). Individuals with higher GCS scores were found to achieve the most favourable outcomes (McIntyre, Mehta, Janzen, Aubut, & Teasell, 2013) but despite this, a large proportion of mTBI sufferers experience persistent behavioural problems following their injury (Ylvisaker et al., 2007). Other measures employed to determine severity of TBI are length of loss of consciousness (LOC) and length of post-traumatic amnesia (PTA). PTA is defined as the period from the injury until the patient is orientated and can form and later recall new memories. A PTA of up to 24 hours leads to categorisation of a mild TBI, a PTA between 1-7 days is classed as a moderate TBI, and PTA longer than seven days results in classification of a severe TBI (Friedland, 2013). However, relying only on the length of PTA may mean the severity of TBI is underestimated, or TBI is undiagnosed. For example, an individual may have only experienced a brief PTA but neuroimaging may indicate presence of lesions. On the other hand, analgesics may affect cognition to the point that individuals present with PTA and are subsequently diagnosed with TBI when one has not occurred (Friedland, 2013).

The Mayo classification system for TBI severity was developed to address the potential unreliability of single systems, and includes GCS, PTA and abnormalities on neuroimaging (Friedland, 2013). There are three main classifications of TBI according to the Mayo system; definite moderate-severe TBI, probable mild TBI (mTBI) and possible TBI. A classification of probable mTBI is made if LOC is less than 30 minutes and PTA lasts less than 24 hours (Friedland, 2013). Residual deficits are common following mTBI and may include changes in thinking, sensation, language, or emotions (Lu, Gary, Neimeier, Ward, & Lapane, 2012). Evidence suggests that a greater proportion of patients older than 60 years sustain what would generally be classified as a mild TBI compared to a moderate or severe TBI (LeBlanc, de Guise, Gosselin, & Feyz, 2006).

Injury identification

Mild cases of TBI are often misdiagnosed or neglected by patients and medical personnel (Powell, Ferraro, Dikmen, Temkin, & Bell, 2008). Rusnak (2013) suggests that this may be the case because the criteria for moderate and severe injuries is well defined, whereas mild cases of TBI (mTBI) are more likely to remain undiagnosed even when patients report findings consistent with an mTBI diagnosis (Powell et al., 2008). Because those with mTBI do not show focal neurological disturbances or structural abnormalities, the injury is often considered irrelevant and patients are unlikely to receive follow-up care (Ramos-Zuniga et al., 2013). Traumatic brain injury has been described as a “silent epidemic”, as long term disabilities are largely invisible (Rutland-Brown, Langlois, Thomas, & Xi, 2006). Arguably, mTBI is even less visible than moderate or severe TBI, with a prevailing expectation that individuals will spontaneously recover. Within this “silent epidemic”, older adults appear to be a silent population (Thompson et al., 2006).

1.3 Incidence and prevalence of TBI

Large cohort and population based studies conducted in New Zealand have reported that over 30% of individuals will have experienced a TBI by the time they are 25 years of age and that the incidence of TBI in New Zealand is approximately 790 cases per 100,000 people per year (Feigin et al., 2013; McKinlay et al., 2008). Across all age groups, males experience more TBI events than females (Leibson et al., 2011) which may reflect differences between sexes in risk taking behaviours, exposure to occupational hazards and involvement in violence (Feigin et al., 2013). The greatest proportion of TBI events are mild (Feigin et al., 2013).

Incidence and prevalence of TBI in older adults

Studies of the incidence of mTBI in the older population are limited as mild injuries are often studied in the context of sporting injuries, which most frequently occur in youth and younger adults. Older adults however, do experience high incidences of TBI. Traumatic brain injury has been found to be the third most common injury leading to hospital admission in those aged over 65 (Rapoport & Feinstein, 2000) and the age-adjusted rate for non-fatal TBI in adults aged 65 years and older is more than double that of the general population (Thompson et al., 2006). Aging is associated with more falls, and more than a third of all TBI cases in one prevalence study were due to falls (Rusnak, 2013). In older adults, falls are the most common cause of TBI (Thompson et al., 2006).

It is therefore clear that TBI is a common injury type across all age groups, more common in males than in females, and that the majority of TBIs are mild. In older adults, the most common mechanism of injury is falls. Due to the high incidence of mTBI in older adults, outcomes for this age group require further investigation.

1.4 Symptoms commonly reported post mTBI

Symptoms can be divided into four areas: somatic, cognitive, sleep, and neuropsychiatric (Sandel, Lovell, Kegel, Collins, & Kontos, 2013), with symptoms in each domain impacting on quality of life and recovery following injury. Commonly reported symptoms following a TBI include disinhibition, irritability, aggression, reduced anger control, immature or inappropriate behaviour, impaired social perception, depression and social withdrawal (Ylvisaker et al., 2007) as well as headaches, memory loss, difficulty concentrating, sleep disturbances and motor unsteadiness (Sandel et al., 2013). Even mTBI can result in reduced cognitive performance on tasks of attention, memory, executive functioning and information processing (Dean & Sterr, 2013). Sleep problems experienced

following mTBI are likely to further negatively affect long term cognitive outcomes (Dean & Sterr, 2013)

Research suggests that compared to younger individuals, older adults may exhibit more severe symptoms and may have poorer outcomes with decreased probability of a good recovery following the injury (Goldstein & Levin, 2001). Long-term recovery following TBI may also differ between age groups. In a participant group including adults who experienced TBIs of varying severities, a smaller proportion of adults older than 50 were rated as achieving good recovery according to the Glasgow Outcome Scale (GOS) one year post-injury, compared to those aged 18-49 (Rothweiler et al., 1998).

Post-concussive syndrome

Post-concussion syndrome (PCS) is one of the most common causes of physical, cognitive and psychomotor disturbances that affects the quality of life, work, and social reintegration of individuals into the community following a TBI (Ramos-Zuniga et al., 2013). In order to meet the criteria for diagnosis of PCS, the patient must exhibit one or more of the following: confusion, disorientation, loss of consciousness for 30 minutes or less, amnesia, focal neurological signs, seizures, or presence of an intracerebral lesion that does not require surgery, and a score of 13-15 on the GCS (Guinto & Guinto-Nishimura, 2013). Commonly reported clinical symptoms of PCS include amnesia, irritability, headache, and emotional distress. The duration of symptoms tends to be variable, and symptoms may persist for up to one year following injury (Guinto & Guinto-Nishimura, 2013). In some cases, PCS may become chronic (Ramos-Zuniga et al., 2013). Although some PCS symptoms respond well to treatment, many of the more common symptoms are resistant to treatment. These include cognitive and memory problems, fatigue, sleep disturbances and depression and irritability (Guinto & Guinto-Nishimura, 2013). Older adults (>40yrs) are less likely to recover

completely from PCS compared to younger adults, that is, permanent PCS has been reported as more likely in older age groups (King & Kirwilliam, 2011).

Externalizing behaviours

Externalising symptoms such as aggression, hyperactivity, irritability and sexual misbehaviour are common following TBI. In adults with mTBI, general irritability has not only shown to be the most common symptom, but has also been found to persist up to one year post-injury in a third of all cases (Ylvisaker et al., 2007).

Depression

The development of major depressive disorder or depressive symptoms following TBI is common. For instance, chronic stress and depressive symptoms are frequently reported by those with mild to moderate TBI, and are strongly associated with post-injury functional status (Bay, Sikorskii, & Gao, 2009). After a TBI, there may be a change in the brain's ability to implement the regular biological stress response and individuals may experience chronic stress; whether due to the traumatic event itself or as a result of the subsequent loss of control over life circumstances like work and relationships (Bay & de-Leon, 2011; Bay et al., 2009). Depressive symptomology can be detected within a week of injury, or in the years following (Bay & Covassin, 2012). For instance, Jorge et al. (2004) observed major depressive disorder (MDD) in one third of patients during the first year after sustaining a TBI. Age is a significant predictor of MDD after TBI and was found to occur more often in those aged 60 years and older compared to 18-29 year olds with TBIs ranging from mild to severe (Papa, Mendes, & Braga, 2012). Those with MDD after TBI additionally report poorer health related quality of life one year post-injury (Papa et al., 2012). Major depression therefore has a negative effect on the recovery process and psychosocial outcomes of patients with varying severities of TBI, particularly those aged older than 60 years.

Substance abuse

Changes in thinking, perceptions, and additional feelings of irritability following TBI may additionally lead to alcohol and substance abuse. For instance, even in those with mTBI, Miller et al. (2013) found hazards for alcohol dependence, nicotine dependence, and non-dependent substance abuse to be significantly elevated after the injury. However, no studies regarding drug and alcohol use after TBI focus on older adults. Nonetheless, drug and alcohol use following TBI may impair recovery outcomes and may exacerbate sequelae of the injury (Bjork & Grant, 2009), and should therefore be carefully monitored.

Second impact syndrome

In addition to the symptoms caused from a single TBI, multiple head injuries can have substantial short and long term effects. For example, second impact syndrome refers to instances when the individual suffers a second trauma within the first few days of the initial trauma. Second impact syndrome may result in a permanent or long lasting cognitive disorder (Guinto & Guinto-Nishimura, 2013). The pathophysiological explanation of second impact syndrome is that following an injury to the head, the brain experiences enhanced vulnerability for up to ten days, during which time there is a loss of cerebral self-regulation, resulting in an increase in intracranial blood volume (Guinto & Guinto-Nishimura, 2013). When the individual sustains a second impact, the brain is no longer able to auto-regulate intracranial and cerebral perfusion pressures. In the worst case scenario, death can occur within two to five minutes (Bey & Ostick, 2009). Given that falls are the most common mechanism of injury for TBI in older adults (Thompson et al., 2006), second impact syndrome is a significant risk for this age group as repetitive falls likely result in repetitive TBI.

1.5 TBI and functional outcomes in older people

Age is a significant predictor of recovery post-TBI (Forslund et al., 2013) and the proportion of adults experiencing unfavourable outcomes increases with age (Stocchetti, Paterno, Citerio, Beretta & Colombo, 2012). For example, following TBIs of varying severities, elderly patients have been found to be less likely to return to pre-morbid functioning, less likely to return to work and to experience greater deficits in activities of daily living and mobility, compared to younger patients (Rapoport & Feinstein, 2000). Variable baseline cognition and memory in older adults may however make it difficult to assess the severity of outcomes (Papa, Mendes & Braga, 2012) and this is often not taken into account in studies of TBI outcomes in older adults.

The more severe consequences of injuries sustained later in life may be a result of poorer compensatory mechanisms in the older brain during initial recovery, or reduced plasticity of the brain (Senathi-Raja & Ponsford, 2010) as well as poorer neuronal reserve and quality in those over 55-65 years (Chua, Ng, Yap, and Bok, 2007). The cognitive decline that is generally seen in older adults can be explained by structural changes in the frontal and medial temporal lobe, and when these age-related changes are combined with brain injury, more pronounced effects may be seen (Goldstein & Levin, 2001).

Not only are older adults more vulnerable to TBI, but once individuals reach the age of 65-70 years, the risk of mortality and morbidity after TBI increases (Gaetani, Revay, Sciacca, Pessna, Aimar, Levi, & Morenghi, 2012), as does the risk for experiencing a TBI in the first place (Rapoport & Feinstein, 2000). Reasons cited for this increased risk include increased incidence of falls in older adults, greater number of motor vehicle accidents and cognitive decline that may act as a predisposing factor for both falls and accidents (Rapoport & Feinstein, 2000).

Many individuals who have suffered a TBI do not return to work for 1-3 months following their injury, and describe decreased self-rated productivity for several months after returning to work (Belanger et. al., 2010). Additionally, older adults are less likely to return to work after TBI than younger adults (Rapoport & Feinstein, 2000). Overall, the evidence suggests that the high incidence of TBI in older adults represents significant economic costs, as well as the more obvious costs to the health and wellbeing of the injured individuals.

Social support and integration

Functioning within one's social context and community integration has been found to be a critical aspect of functional status following TBI (Bay et al., 2009; Forslund, Roe, Arango-Lasprilla, Sigurdardottir, & Andelic, 2013). Additionally, effective social support from the patient's family has been found to be significantly related to lower levels of depression following TBI (Rauch & Ferry, 2001).

Following TBI, adults have reported social communication skills deficits which are associated with lower ratings of community integration and satisfaction with life. Significant others and clinicians additionally report social skill problems in individuals with TBI, and tended to report more problems than individuals themselves (Dahlberg et al., 2006). Older adults in particular who lack social support following the injury may be more likely to exhibit depressive symptoms and exhibit lower functional status post-injury (Bay et al., 2009).

1.6 Available treatment and interventions

Rehabilitation following TBI aims to help the individual achieve the maximum degree of pre-injury functioning, within any physical and cognitive limits imposed by their injury (Chua, Ng, Yap, & Bok, 2007). Prompt physical and psychological rehabilitation is imperative to ensure the patient is again able to participate in activities carried out prior to the

injury (Guinto & Guinto-Nishimura, 2013). A range of interventions have been developed in order to aid recovery following TBI. Such interventions include early nutritional supplement, therapeutic hypothermia, pharmacologic interventions, cognitive rehabilitation and psychotherapy (Chua et al., 2007; Lu et al., 2012). However, these treatment options appear to focus on the rehabilitation of the more severely injured, with the final goal of reintegrating patients into the community. For instance, Lu et al. (2012) describe how, following stabilisation of the patient's condition, attention is directed towards rebuilding neurobehavioural and psychosocial skills needed for community reintegration. There have been, however, considerable advances in the treatment and remediation of symptoms following TBI, particularly with regard to cognitive functioning. These include therapies that specifically target sustained, selective, and divided attention, as well as task-specific working memory (Chua et al., 2007).

Available treatment and interventions for older adults

Despite findings that older individuals may suffer worse outcomes following a TBI, it has been suggested that older patients may not be treated with as much care and energy as younger patients (Mak et al., 2012) and little research focuses on optimal rehabilitation types for older individuals. Input following the injury is likely to be limited or insufficient for older adults because this age group has traditionally been expected to have poorer outcomes despite adequate rehabilitation (Mak et al., 2012). However, the cognitive decline that is generally seen in older adults can be explained by structural changes in the frontal and medial temporal lobes and variation in outcomes according to age may implicate age-related variations in mTBI pathology, although the cause of these variations are not clear (Rapoport & Feinstein, 2000). Older adults are also more at risk for subdural and intracerebral bleeds and contusions which may account for their poorer outcomes (Rapoport & Feinstein, 2000). Additionally, the combination of structural brain changes associated with normal aging and those exhibited

after TBI may lead to increased effects following the injury. However, recent studies have shown that the outcome of older adults after TBI can in fact match those of younger adults when these patients are offered intensive rehabilitation and their needs are properly understood (Mak et al., 2012).

Failure to recognise that older brain injured patients often present with different and often more severe physiological and psychological needs limits the recovery of these individuals (Thompson et al., 2006). Poorly treated TBI in older adults may result in greater dependence on carers, earlier rest home placement, decreased quality of life, and increased healthcare burden, in addition to the previously discussed mood and substance abuse problems. Older individuals experiencing TBI may also be more likely to experience further complications after their injury, which may contribute to the higher mortality and morbidity rates in this group (Thompson et al., 2006). It is therefore essential to identify factors that may contribute to problems following TBI in order to develop effective rehabilitation programmes and provide relevant support. Such interventions will result in optimal long term outcomes for those who have suffered a TBI.

In order to address concerns related to rehabilitation for older adults following TBI, Chua et al. (2007) suggested a comprehensive rehabilitation programme designed specifically for elderly patients that takes their individual needs into account. For example, Chua et al. (2007) discussed how social issues are more relevant for older patients who have experienced a TBI compared to younger patients, and that prolonged community support following discharge may be necessary in order to maintain function. A lack of social support may additionally affect the ability of older adults to return to independent living (Goldstein & Levin, 2001). Furthermore, a multidisciplinary approach to the prevention of falls is likely to reduce instances of further TBIs. Such an approach may include addressing behavioural problems, environmental modifications, and the use of exercise programmes targeting balance training

(Chua et al., 2007). Goldstein and Levin (2001) additionally suggest that injury classification criteria may need revision in older people, given their differing needs.

1.7 Summary and rationale for the current study

TBI is a common injury across a range of ages, and results in a wide range of symptoms affecting a number of domains, including cognition, behaviour and mood. Following TBI, older adults experience poorer functional, social and psychological outcomes than younger individuals, and may not receive a level of rehabilitation that is necessary for optimal recovery.

Despite the poorer prognosis for recovery following TBI in older individuals, minimal research has focussed on ways in which rehabilitative input can be improved for those over 55 years of age. Very few studies focus specifically on older adults who have experienced mTBI, and even fewer studies examine care or rehabilitation provided for this age group. However, it is not appropriate to see treatment for TBI as universal across all ages, as it is evident that older adults have been shown to have more varied needs and often more complicated outcomes than younger individuals.

Given the rapidly increasing older population, there is an urgent need to develop a better understanding of TBI in older adults. It is important to investigate the level of support and rehabilitation that is currently provided to older adults, and to identify any areas in which rehabilitation and support can be improved for this group. This requires an understanding of interventions that are currently provided and information regarding where patients have experienced difficulties following their injury.

2. Rehabilitative input and support for older people experiencing TBI: A pilot study

2.1 Method and Results

A pilot study was conducted with 39 adults aged 22-89 years ($M = 61$; 28 males, 11 females). The purpose was to evaluate the level of rehabilitative support that older people receive after mTBI, and to compare this to the support received by younger adults. All participants had experienced a mTBI in the past six months but no less than three months prior to being contacted, and were randomly selected from the attendance register at Christchurch Hospital's Emergency Department. This selection of patients were each mailed a consent form, copy of the questionnaire and letter inviting participation, and were phoned back at a later date to arrange an interview time. Ethics approval for this study was obtained from the Upper South A Regional Ethics Committee.

Consenting participants were initially placed into the following four age bands to allow evaluation of information and rehabilitative support across ages; 18-25 ($N=1$), 25-50 ($N=10$), 50-65 ($N=12$), 65-80 ($N=16$). However, participants were later combined into two age groups for analysis.

Participants were questioned about their experiences following their TBI by phone. Questions focussed on information and treatment they received following the injury, but also included questions about post-injury cognitive and mood problems. For instance, participants were asked if they experienced any difficulties remembering or concentrating, any fatigue, irritability, sensitivity to loud noises or light, difficulties with movement or thinking. The inclusion of symptoms was based on those detailed in the Rivermead Concussion Checklist (Crawford, Wenden, & Wade, 1996). Participants were also asked what information and

assistance they received following their injury, whether they found this useful, and if any other information or types of assistance would have been helpful to them.

A quantitative analysis of the phone questionnaire responses was performed. A third of participants reported that they received no information following their injury, and a fifth of participants did not remember what information they received, if any. Following this preliminary analysis, participants' responses were examined within two age bands (18-50 yrs and 50-85 yrs) to enable direct comparison between older and younger adults. Results are shown in Table 1. The older group contained a greater proportion of participants who did not remember what information they were given. This group also contained the most participants who did not receive any information following their injury. Participants in the younger group were most likely to report having received verbal or written information following their injury. One participant in the older group said that they did not expect any information as their injury was mild and they did not experience any symptoms post-injury.

Table 1.

Information received by participants following their injury, grouped by age.

	No info	Don't remember	Fact sheet given to family	Verbal or written information	Mild injury (didn't expect any information)
<i>Age Group</i>					
1: 18-50yrs	27.3%	18.2%	9.1%	45.5%	-
2: 50-80yrs	34.5%	24.1%	10.3%	27.6%	3.5%

All percentages rounded to 1dp.

In addition to the information participants received following their injury, we also examined responses regarding how input and information received could have been improved. Across all ages participants noted the potential usefulness of extra follow up appointments and information about symptoms to expect as a result of their injury. A number of participants suggested that it may have been useful for their families to receive some kind

of support or more information about the injury and subsequent symptoms, particularly where family members had a significant input in the patient's recovery. Older participants stated that they would have liked help getting around and to appointments, as mobility was often limited following their injury. Participants in the oldest group also said they would have found home help useful.

Additional analyses regarded symptoms experienced by individuals following their injury, both as a group and within in each band. Common problems experienced across all ages included fatigue (66.7%), concentration difficulties (51.3%), and difficulty thinking (46.2%) and remembering (46.2%). See Table 2 for a breakdown of symptoms experienced by the two age groups. There were no significant differences between the two age groups for any of the symptoms listed.

Table 2.

Proportion of individuals who experienced specific symptoms post-injury.

Symptom	Proportion of all participants	Proportion aged 18-50	Proportion aged 51-85
Memory	46.2%	36.4%	48.3%
Concentration difficulties	51.3%	54.5%	44.8%
Fatigue	66.7%	63.6%	65.5%
Irritability	35.9%	45.5%	31.0%
Sensitivity to light	33.3%	54.5%	24.1%
Sensitivity to noise	30.8%	36.4%	27.6%
Movement difficulties	35.9%	36.4%	34.5%
Thinking difficulties	46.2%	45.5%	44.8%

All percentages to 1dp

2.2 Conclusions and limitations

The pilot study clearly illustrated that all adults experience a range of problems following a TBI, and that information received following the injury is often limited and insufficient for optimal recovery. A lack of information following a TBI may result in increased frustration, anxiety and depression.

The pilot study did not find report of post injury symptoms to differ significantly across the two age groups. However, participants were often vague on their descriptions of symptoms, and rarely elaborated on the extent of the symptoms. Additionally, it is possible that participants in the older age group experienced a number of the listed symptoms prior to the injury, so failed to include these in post-injury symptomology.

A final possible limitation of the pilot study is the small sample size and unequal distribution of adults in each of the age groups. For instance, the youngest group had only one participant. Even when divided into two age groups, the older group contained more than double the number of participants. Although the primary aim of the study was to address rehabilitative input following TBI in older adults, it is still necessary to have a sufficiently sized group of younger adults to which to compare outcomes.

3. The current study

The current research builds on the pilot study reported above, and was designed to address several problems with that study. For instance, the current study was designed to ensure equal and sufficient numbers of participants were recruited into each age band to allow reasonable comparisons to be made across groups. Additionally, verbal probing of dichotomous questions was undertaken by the interviewer to ensure participants elaborated on their answers. This allowed us to develop a relatively comprehensive picture of the symptoms experienced by individuals and the support and assistance they received, and enabled us to compare such findings across age groups.

The overall aim of this study was to evaluate the level of input received by older individuals (51+) compared to younger individuals (<51 years of age) following mTBI.

Our aims and hypotheses are therefore as follows:

1. *Aim:* To evaluate whether older adults are more likely to experience negative emotions or depressive feelings and memory and cognitive problems and difficulties after mTBI.

Hypothesis: Older adults are more likely than younger adults to have experienced memory and cognitive difficulties, negative emotions and/or depressive feelings following mTBI.

2. *Aim:* To examine whether there are any differences in the quantity of information received by older adults following mTBI, compared to younger adults.

Hypothesis: Older adults will receive less information than younger or middle-aged adults following mTBI.

3. *Aim:* To evaluate the level of rehabilitative support and assistance that is received by older adults following mTBI, and to compare this to the support and assistance received by younger adults.

Hypothesis: Older adults will receive less support and assistance than younger adults following mTBI.

4. *Aim:* To evaluate whether older adults are more likely to express dissatisfaction with the information and/or support and assistance received following their injury.

Hypothesis: Older adults are more likely than younger adults to express dissatisfaction with the information and support/assistance received following mTBI.

Thus, we aim to evaluate the symptoms experienced by individuals after mTBI and compare these across ages, within an adult population. We also aim to investigate information that is received by older people following mTBI, and to compare this to that received by other age groups. Additionally, we will obtain reports of support and rehabilitative input received by patients following their injury. Such support may include

assistance from the Accident Compensation Corporation (ACC), home help, and physiotherapy. Information will be gathered across a range of age groups (18-85 years) which will enable us to compare symptoms and the level of care and support received by both younger and older adults following mTBI.

The current research will contribute considerably to knowledge regarding the extent of rehabilitative input for older people who have experienced traumatic brain injuries. Currently, the majority of research into traumatic brain injuries has focussed on those experienced by children or working age adults, and the experiences of older adults have been somewhat neglected. If, as proposed, it is found that older adults receive limited input or rehabilitative support following their injury, this research will highlight areas in which input could be improved. Collection of data highlighting specific problems experienced by patients will also indicate any age differences in symptomology, as well as the way in which such symptoms were treated.

4. Method

4.1 Participants

Cases of TBI were identified retrospectively by an electronic audit of all individuals above 18 years admitted to a Canterbury District Health Board (CDHB) hospital over the previous 12 months. A search was performed of all names on the CDHB Patient Management System who came through the Emergency Department (ED) and who had an entry descriptor of 'Head Injury' or 'Brain Injury'. An audit of ED entries in the patient medical record revealed whether the diagnosis was in fact a TBI. Patients were excluded if they had been admitted to hospital for more than observation or if they had other serious injuries and were moved to another ward from ED.

Individuals who met the inclusion criterion were divided into four age groups; 18-30, 31-50, 51-65 and 66-85 years of age to allow for comparison of services received by age and incidence and prevalence of TBI at each age group. A total of 250 individuals were identified and contacted by mail. They were sent a consent form, a copy of the questionnaire, and a letter from an ED doctor inviting participation (See Appendices A, B and C, respectively). These individuals formed the potential pool of participants for the study. Participants were excluded if they were unable to speak or understand English. Of the total 250 potential participants, 106 consented to participation. Of those participants who gave consent, we contacted the first 80 (75.8%) to gain a balance of 20 participants in each age group. a total of 80 (75.8%) were able to be contacted ($M_{\text{age}} = 48$, $SD_{\text{age}} = 19.77$). There were 53 males and 27 females.

4.2 Materials

A questionnaire developed specifically for the pilot study was used. This questionnaire asked participants about their experiences following their TBI. Questions focussed on information they were given and any treatment that was received, but also included questions about any cognitive and mood problems experienced following the injury. Participants were additionally asked to suggest any information of assistance that would have been helpful to them following their injury. A copy of this questionnaire can be found in Appendix B.

4.3 Design

This study was a mixed methods design; both quantitative and qualitative methods of research were applied.

4.4 Procedure

In addition to a copy of the questionnaire, a brief description of the study was posted out to individuals identified as potential participants. A letter also advised potential participants of an upcoming phone call from the researcher. Consent for participation was given orally at the time of the initial phone call. Those adults who consented to participation were phoned back at a later date at a time of their choice.

The interview was a 5-10 minute long structured telephone phone interview and answers were hand transcribed by the researcher. No identifying information was recorded on transcripts of the interviews; each participant was assigned a code that described only which of the four age groups they belonged to. The researcher recorded responses from participants verbatim where possible, and when required to paraphrase responses the researcher ensured these reflected the thoughts of the participant. This study was given approval by the Upper South A Regional Ethics Committee.

4.5 Data Analysis

Qualitative Analysis

Qualitative analysis of the data was performed using an inductive coding method (Thomas, 2003). Using this method, coding was directed by the content of the data. Codes were developed for responses to all questions without dichotomous answers; that is, questions one, six, seven and nine.

Initially, familiarisation with the data was achieved by reading and re-reading transcripts in order to become familiar with the content of each. Succinct labels (codes) were then generated to enable identification of important features of participant's responses for each question. Following initial development of codes, these were revised to ensure they were concise and relevant. For instance, for question one, written information came to

include fact sheets, pamphlets, print outs and any other similar material received by the participant.

During the process of developing codes it became apparent that participants often answered earlier questions later in the survey. For example, when asking participants if any other type of assistance would be helpful (question 9) they often also discussed information that they would have liked to receive (applicable to question 6). Where this was the case, responses were coded to apply to the more relevant question.

Statistical analysis

Quantitative data analysis was performed on PASW Statistics for Windows, Version 18.0 (2009). Chicago: SPSS Inc. and Microsoft Excel Version 14.0 (2010), Redmond, Washington: Microsoft. Analyses were initially performed for each of the four age groups, but subsequently the four groups were collapsed into two to enable clearer analysis.

5. Results

5.1 *Symptoms experienced by individuals*

Participants were asked whether they experienced any concussive symptoms after their injury (yes or no response). Females reported having experienced problems more often than males, $F(1, 78) = 4.680, p = 0.03$. There were no age differences for whether participants reported to experience symptoms or not ($F(3, 76) = 0.640, p = 0.59$).

Participants were then asked if they had experienced any of a possible 8 symptoms. These symptoms were included based on the concussion signs and symptoms checklist (Center for Disease Control, 2010; Accident Compensation Corporation, n.d.). On average, individuals experienced about 3 of 8 possible symptoms following their TBI ($M = 3.03, SD = 2.67$).

There were no significant differences between males and females for the number of symptoms they experienced, $F(1, 78) = 0.042, p = 0.84$, see Table 3.

The proportion of participants who experienced each of the eight symptoms is shown in Table 3. Across all ages, the most common symptom experienced post-TBI was fatigue (48.8% of participants), followed by problems with concentrating and memory, both experienced by 43.8% of participants. The least commonly experienced symptom was difficulty with movement, including balance, experienced by 26.3% of participants.

Table 3.

Proportion of individuals who experienced specific symptoms post-injury.

Symptom	Proportion of all participants	Proportion male	Proportion female
Memory	43.8%	28.8%	15%
Concentration difficulties	43.8%	26.3%	22.5%
Fatigue	48.8%	30%	18.8%
Irritability	27.5%	17.5%	10%
Sensitivity to light	36.3%	23.8%	12.5%
Sensitivity to noise	32.5%	25%	7.5%
Movement difficulties	26.3%	17.5%	8.75%
Thinking difficulties	41.3%	26.25%	15%

All percentages rounded to 1dp.

The oldest group reported the fewest symptoms post-injury ($M = 2.40, SD = 2.98$), followed by the youngest group ($M = 2.90, SD = 2.53$), and the second and third groups, respectively ($M = 3.35, SD = 2.70$; $M = 3.45, SD = 2.50$). A one way ANOVA determined that there were no significant differences between age groups for the number of symptoms experienced by individuals, ($F(3, 76) = 0.176, p = 0.91$).

A chi-square test of independence was performed to examine the relation between age groups for each of the 8 specific symptoms. Sensitivity to light was the only post-injury symptom that neared a significant relation with age, $\chi^2(3, 80) = 7.09, p = 0.07$. The mean number of individuals who experienced post-injury sensitivity to light in the youngest group

($M = 0.55$, $SD = 0.51$) was significantly greater than in the oldest group ($M = 0.15$, $SD = 0.36$), $p = 0.04$.

In addition to the eight possible post concussive symptoms that were directly asked about, individuals were given the opportunity to discuss any other symptoms they may have experienced after their TBI. Participants noted a range of symptoms, including dizziness, headaches, nausea, blurred vision and coordination difficulties, as well as problems remembering and concentrating. Some participants ($n = 4$) also discussed other injuries that may have overshadowed any symptoms occurring as a result of the TBI, such as injuries to limbs or joints.

5.2 Information received by individuals

Participants reported being given a range of information, from a variety of sources. Information ranged from nothing at all, to verbal and written information given either to the patient themselves or to family members, as well as information about expected symptoms. Types of information received by participants were initially analysed according to the four age groups (See Table 4). Note that participants sometimes reported receiving more than one source of information. Those in the oldest group (66-85 yrs) were the most likely to respond that they had not received any information, and those in the youngest group (18-30 yrs) were the most likely to receive information about symptoms to expect. Information reported by participants also included information about when to return to hospital or to visit a GP (reported by 13.75% of all participants). However there were no significant differences between the four age groups for the type of information that was received. A quarter of participants (26.5%) did not receive any information following their TBI. Across all ages, verbal or written information about symptoms to expect was the most commonly received, followed by more general verbal information.

Table 4.

Frequency of information types received by participants in each age group

Age Group	<i>Don't remember</i>	<i>None</i>	<i>Written</i>	<i>Written (family)</i>	<i>Verbal</i>	<i>Verbal (family)</i>	<i>Return</i>	<i>Sympts</i>
1: 18-30	5%	2.5%	7.5%	0	8.8%	0	1.3%	13.8%
2: 31-50	5%	6.3%	10%	1.3%	6.3%	2.5%	5%	7.5%
3: 51-65	6.3%	6.3%	6.3%	0	10%	1.3%	5%	7.5%
4: 66-85	3.8%	11.3%	5%	1.3%	6.3%	2.5%	2.5%	6.3%
Total percent	20%	26.5%	28.8%	2.5%	31.3%	6.3%	13.8%	35%

All percentages rounded to 1dp.

For all groups, $n = 20$ *Return:* Explanation about when the patient should return to the hospital or to see a GP*Sympts:* Information about symptoms the patient should expect

To further analyse group differences, we combined participants into two age groups; younger (18-50yrs) and older (51-85yrs). The proportion of each type of information received by participants in these two age groups is reported in Table 5, along with examples given by participants. Again, a greater proportion of those in the younger group received information about symptoms to expect and a greater proportion of those in the older group did not receive any information.

Table 5.

Information received by participants (older and younger) after TBI

<i>Q1: Thinking about your time you had your head injury what information were you given?</i>		
	18-50yrs ($n = 40$)	51-85yrs ($n = 40$)
DR	20%	20%
	"Can't really remember"	"Can't recall."
NI	17.5%	35%
	Participant also damaged vertebrae and received information about that but not about their TBI.	"Hospital was good but gave no information".
W	35%	22.5%
	"Pamphlet from hospital about head injury"	"Got given a print out of concussion in adults when discharged from A&E."
WF	2.5%	2.5%
	Participant's wife received an information sheet.	Participant's daughter received a pamphlet and verbal information on

		discharge.
V	30%	32.5%
	Explained how serious the injury was	“if continued headaches or problems told to go to GP”
VF	5%	7.5%
	Hospital staff explained information about symptoms to participant’s mum.	Hospital staff told participant’s daughter symptoms to look out for.
R	12.5%	15%
	Told to go back to hospital if felt dizzy.	“Sent home with information about when to return to hospital”
SYM	42.5%	27.5%
	Participant was told about expected problems, dizziness etc.	Medical staff explained what had happened, symptoms that may occur and how to handle these.

All percentages rounded to 1dp

DR: Don’t remember – the participant did not remember what information they received (if any)

NI: No information received

W: Written information (including fact sheet/pamphlets, hospital print outs)

WF: Written information (as above) was given to family.

V: Verbal information, for example explanations of what had happened and what symptoms patients should expect

VF: Verbal information given to family members or significant others

R: Explanation about when the patient should return to the hospital or to see a GP, that is, what symptoms a patient should be concerned about.

SYM: Information about symptoms the patient should expect, including information about what symptoms the patient should worry about, i.e. when to see a doctor.

Satisfaction with information received

The majority of participants reported being satisfied with the information they received following their injury (76.3%, $n = 61$). However, 12.5% ($n = 10$) of participants did not receive any information at all, and 11.3% ($n = 9$) of participants were not satisfied with the information they received. Table 6 depicts participant’s satisfaction with information received according to each age group. The two oldest age groups contained the largest proportion of individuals who were dissatisfied with the information they received following their injury. More individuals (17.5%) in the oldest groups (51-85yrs) were not satisfied with the information they received, compared to only 5% of individuals in the youngest two groups combined. The oldest two age groups additionally contained the greatest proportion of

individuals who did not receive any information at all. However, an ANOVA did not report any significant differences between the four age groups, $F(3, 76) = 0.597, p = 0.62$.

Table 6.
Satisfaction with information received

Age group	<i>Happy</i>	<i>Not Happy</i>	<i>N/A (none)</i>
1: 18-30	29.5%	11.1%	10%
2: 31-50	27.9%	11.1%	20%
3: 51-65	19.7%	55.6%	30%
4: 66-85	23.0%	22.2%	40%

All percentages rounded to 1dp.
For all groups, $n = 20$

Table 7 depicts a breakdown of satisfaction with information received for the oldest and youngest age groups. Again, ANOVA did not report any significant differences between groups, $F(1, 78) = 0.051, p = 0.821$.

Table 7.
Satisfaction with information received

Age group	<i>Satisfied (n)</i>	<i>Not Satisfied (n)</i>	<i>N/A or none (n)</i>
1: 18-50 ($n=40$)	87.5% (35)	5% (2)	7.5% (3)
2: 51-85 ($n=40$)	65% (26)	17.5% (7)	17.5% (7)

All percentages rounded to 1dp.

Other information that would have been useful

Some key themes arose from the data regarding the information patients would have liked to receive following their TBI. Although 64% of participants said that no other information would have been useful to them, or could not think of anything, other participants were able to describe information they would have liked to receive following their injury. Such responses were coded and attributed to three possible information types; information about possible or expected symptoms; more general information about TBI, including about recovery; and recognising that an injury had actually occurred. Significantly more females (33.3%) suggested the usefulness of information regarding symptoms than

males (7.5%), $F(1, 78) = 9.57, p < 0.01$. Response proportions for all four age groups are reported in Table 8.

Table 8.

Frequency of type of information participants in each age group would have liked to receive post-injury

Age group	Symptoms	Injury recognition	General info	None
1: 18-30	3.8%	5.0%	8.8%	13%
2: 31-50	3.8%	1.3%	5%	18%
3: 51-65	6.3%	1.3%	7.5%	15.0%
4: 66-85	2.5%	0	6.3%	19%
Total percent	16.3%	7.5%	27.5%	64%

All percentages rounded to 1dp.

For all groups, $n = 20$

We then collapsed participants into two age groups (older and younger) to more clearly depict differences between age groups. Response proportions and examples for the two collapsed age groups are recorded in Table 9. Note that some participants gave multiple responses.

Table 9.

Suggestions of useful information after a TBI.

<i>Q6: Would any other information been useful to you after your injury?</i>		
	18-50yrs (n = 40)	51-85yrs (n = 40)
SYM	15%	17.5%
	“Information about being sensitive to noises...little things that weren’t expected.”	“Something related to what symptoms to expect.”
IR	12.5%	2.5%
	“Recognition. It was frustrating medical staff not providing any help initially.”	Participant thought they should have taken the injury more seriously.
GI	27.5%	27.5%
	Participant would have liked a written pamphlet about TBI.	“Would have known what to do if given more information.”
NO	60%	67.5%
	“No it was really good.”	“No I had everything I required.”

All percentages rounded to 1dp.

IR: Injury recognition; promptly recognising that an injury had occurred.

GI: More information in general, including information about TBI, information about how ACC works and information about recovery.

NO: No suggestions. Included when participants were already content with what information they received.

Chi-square tests for independence indicated that there were no significant relations between age groups for information that participants would have liked to receive or would have found helpful following their injury.

Participants most often discussed a need for more information in general. Examples of general information included information about how ACC works and written information about TBI and recovery. Responses were also coded as general information when participants were not able to give specific examples of information they would have liked. Participants also commonly said they would have liked more information about symptoms to be expected and what symptoms they should be concerned about. For instance, a 50yr old participant stated:

“Symptoms [from a TBI] can be scary when you’re not expecting them”

Furthermore, some participants noted inconsistencies between the information they were given and symptoms they actually experienced. For instance, in the words of a 62 year old participant:

“[The] hand out said I’d be fine after 2-3 weeks, but talking to nurses and other people with TBI was more useful”

7.5% of all participants would have liked better injury recognition. For instance, participants thought medical professionals should have taken the injury more seriously, or recognised that an injury had occurred sooner. For example, two participants continued playing sport after their injury. Another participant expressed frustration with the lack of help initially provided by medical staff:

“[The] manager of the team didn’t think it was a serious injury” (29yr old participant)

5.3 Additional assistance received

71.3% of participants said they received additional assistance following their injury. There were no significant differences between age groups for whether additional assistance was received, $F(1, 78) = 0.54$, $p = 0.47$. All participants who reported to receive additional assistance following their injury were happy with this. This assistance included help and support from ACC, family members, and friends, as well as physiotherapy and other medical assistance. Medical assistance included hospital stays and follow up phone calls from the hospital or GPs. Participants’ descriptions of additional assistance received were coded and attributed to eight possible categories. These categories are presented in Table 10.

Table 10.

Frequency of post-injury assistance received by participants in each group

Age group	Family	Friends	Sig. Others	ACC	Physio	Psych	Home help	Medical
1: 18-30	8.8%	2.5%	2.5%	5%	2.5%	1.3%	0	3.8%
2: 31-50	12.5%	3.8%	7.5%	2.5%	1.3%	0	0	1.3%
3: 51-65	8.8%	5%	7.5%	2.5%	2.5%	0	0	0
4: 66-85	12.5%	3.8%	7.5%	5%	1.3%	2.5%	1.3%	2.5%
Total %	42.5%	15%	25%	15%	7.5%	3.8%	1.3%	7.5%

All percentages rounded to 1dp.

For all groups, $n = 20$

The proportion of participants who received each type of assistance and examples are detailed in Table 11. Because there were no significant differences between the four age groups for the types of assistance received, data with examples is presented for two age groups (younger; 18-50yrs and older; 51-85yrs).

Table 11.

Assistance received by participants after TBI

<i>Q7: Did you receive any other assistance after your injury?</i>		
	18-50yrs (n = 40)	51-85yrs (n = 40)
FAM	42.5%	42.5%
	“Help from family with driving for a few days.”	Participant’s granddaughter was present at the time and stayed with the participant for a while.
FR	12.5%	17.5%
	“Had to move in with friends.”	Participant’s friends helped with taking the participant to hospital and other tasks.
SO	20%	30%
	Participant’s partner looked after the participant.	“Good support from friends and partner.”
ACC	15%	15%
	“ACC for time off work.”	“ACC helped.”
PHY	7.5%	7.5%
	ACC referred the participant to physiotherapist.	ACC covered a rehabilitation nurse.
PSY	2.5%	5%
	“Saw psychologist”	Participant uses Lifeline.
HH	0	2.5%
		Participant receives home help once a week.
MED	10%	5%
	Participant received a follow up phone call from the hospital.	Participant visited their GP 3 days after their TBI and then again later.

All percentages rounded to 1dp.

FAM: Assistance/support from family

FR: Assistance/support from friends

SO: Assistance/support from significant others (i.e. partners)

ACC: Any assistance from ACC (including if ACC paid for the ambulance)

PHY: Physiotherapy (including visits to Burwood Hospital or other rehabilitation clinics)

HH: Home help – any help with cooking and cleaning (including Meals on Wheels and Nurse Maude)

MED: Assistance from hospital, GP or other medical staff

The most common assistance received following the participants’ TBI came from family or significant others, followed by friends and ACC. Family and significant others were reported by participants to be particularly useful; they helped with driving and performing general daily tasks, as well offering support and reassurance.

Some participants who did not receive assistance for their TBI reported receiving ACC or medical assistance for their other injuries. Assistance received for other injuries was excluded from analysis. Few participants received any psychological help or counselling ($n =$

3), and those who did were all females. Only one participant received home help, although the participant was already receiving this assistance prior to their injury.

Suggested post-injury assistance

Participants were asked if any other type of assistance would have been helpful to them following their TBI. Responses were coded to fit into eight possible groups; home help, psychological help/counselling, assistance with transport, follow up, general info, financial assistance (including ACC), physiotherapy, or none. Again, participants' responses were often coded to more than one category. Assistance requested by participants is reported in Table 12 for all four age groups.

Table 12.

Frequency of type of additional assistance requested post-injury in each age group

Age group	Home help	Psych	Transport	Follow up	General Info	ACC	Physio	None
1: 18-30	0	0	1.3%	0	5%	2.5%	1.3%	16.3%
2: 31-50	1.3%	0	1.3%	5%	2.5%	2.5%	0	16.3%
3: 51-65	1.3%	5%	0	3.8%	2.5%	0	0	17.5%
4: 66-85	1.3%	3.8%	0	1.3%	1.3%	2.5%	1.3%	18.8%
Total %	3.8%	8.8%	2.5%	10%	11.3%	7.5%	2.5%	68.8%

All percentages rounded to 1dp.

For all groups, n = 20

Following analysis of all four age groups, we examined suggestions participants made about assistance they would have found helpful. Table 13 depicts examples of assistance suggested and proportion of participants who suggested this assistance for the younger and older groups.

Table 13.

Assistance suggested by participants to be useful after TBI.

<i>Q9: Would any other type of assistance been helpful?</i>		
	18-50yrs (n = 40)	51-85yrs (n = 40)
HH	2.5%	5%
	“Home help.” – participant was unable to cook for her family	Participant would have liked a cleaner and home help as was often too tired to complete

		housework and lives alone.
PSY	0	17.5%
		“Maybe a support group” – with people who have had a TBI before.
TR	5%	0
	Participant would have liked help getting to appointments as was unable to drive.	
FU	10%	10%
	Participant suggested follow-up to compare functioning and wellbeing before and after the injury.	“Hospital follow-up would have been good.”
GI	15%	7.5%
	“Emphasis on how serious multiple head injuries can be.”	“Should be some information that head injury effects can remain for an extended period.”
ACC	10%	5%
	“Better support from ACC.”	“Everything from ACC was about spinal injury -they ignored the head injury.”
PHY	0	2.5%
		“Physio”

All percentages rounded to 1dp.

PSY: Psychological help or counselling

TR: Help with transport or transport costs

FU: Follow up phone call, letter or appointment

GI: General information – including more information about the injury, expected symptoms and long term prognosis as well as information about precautions participants should take post-TBI and information regarding what help was available to them, such as ACC.

An chi-square test reported a significant relationship between age groups and the request of psychological help/counselling, with a higher mean in the oldest of the two age groups, $\chi^2(3, 80) = 7.98, p = 0.05$. Only the oldest two groups discussed how this help may have been useful. For instance, a participant in the third oldest age group (51-65yrs) stated that it would have been useful to have a number to call to discuss concerns. The participant spoke of how they felt isolated and that although medical professionals are helpful, they don't usually know what the patient is going through. Similarly, a 76 year old participant discussed how he would have liked to talk to someone about his problems as he felt like his condition degraded very quickly. Speaking about the time following their TBI, a 71 year old participant said, “it is a lonely time.”

As shown in Table 6, general information was the most commonly suggested additional assistance that participants said they would have found useful. Follow up was the second most common suggestion. Participants who suggested this would have liked a follow up phone call or appointment to check that they were recovering well, and so that any questions about symptoms or recovery could be answered by a medical professional. Home help was discussed by three participants (all female), and by our definition encompassed help with cooking and cleaning. For instance, one 54 year old participant discussed how a cleaner would be helpful, as fatigue often made it difficult to complete housework as they lived alone with no family or friends nearby. Another participant (41 year old single parent) identified difficulties with cooking and getting children to school due to fatigue.

Two participants discussed how they would have liked assistance with transport. For instance, even when physiotherapy was offered to participants, they discussed difficulty in getting to these appointments. As participants pointed out without being able to drive, travelling from one side of the city to the other can be very time consuming, especially when experiencing fatigue, irritability and difficulties with memory.

Although only four participants specifically stated that they would have liked more assistance from ACC or with financial matters, many participants discussed frustration in dealing with ACC (10% of all participants). For instance, regarding ACC, a 36 year old participant said they were “waiting for a long time before knowing what was going on” Similarly, a 41 year old participant said they waited three months for ACC to decide whether they would compensate or not, and they received no income during this time. This participant also experienced a lot of conflict between experts, and became confused about who to believe. The experience of many of our participants with ACC is well illustrated in the following statement:

“It’s traumatic enough going through the TBI as it is, let alone all the fighting between agencies and difficulty trying to gain any compensation from ACC”. (41yr old participant)

Even when ACC did compensate individuals for time off work, this was not always sufficient. For instance, one participant in the youngest group spoke of frustrations with ACC as they did not provide financial support for the whole period the participant had to take off work. Similarly, another participant stated how ACC urged them to return to work before they were fully recovered, which caused unnecessary stress.

Those who did not provide any suggestions as to assistance that would have been useful included those who did not experience any problems or who did not think their injury was very serious ($n = 40$, 50%) and those who already had good support from friends and family ($n = 6$, 7.5%). For instance, two participants in the second age group (35-50yrs) said they “didn’t think it was a big deal” and that they did not need any extra assistance as they “could still continue normal life”. Other participants recognised the usefulness of support from their family stating, for example, that they were “lucky to have strong family support,” that the “hospital visit and wife were enough” and that “family and friends were very supportive and that was enough”

The remaining 11.25% of participants who did not give any suggestions for additional help were happy with what they received.

6. Discussion

A major focus of this study was to examine the mTBI symptoms experienced by younger adults (<50years) versus older adults (>50 years). We found that individuals, regardless of age, experienced a range of symptoms with fatigue and difficulties with memory and concentration being the most commonly reported. Participants also noted other

symptoms such as dizziness, headaches and nausea, although these were less common. All reported symptoms were consistent with those expected post-TBI and reliably reported in the literature regarding this injury group (Ylvisaker et al., 2007; Sandel et al., 2013; McKinlay et al., 2013; Dean & Sterr, 2013). However, there was no significant difference in the number or type of symptoms reported regardless of age. We also evaluated whether younger adults received different information or support following mTBI compared to older individuals. Information received by participants at point of injury varied, and one quarter of participants did not receive any information at all. As hypothesised, a lack of information was most commonly reported by those in the oldest age group (66-85yrs). Although the majority of participants were happy with the information they received following their injury, the oldest two age groups contained the largest proportion of individuals who were unhappy with the information they received following their injury. We found participants struggled to suggest additional information that they would have found useful but suggestions included more information about symptoms to expect and general information, including about ACC and recovery from TBI. All participants who received additional assistance after their injury (71.3% of participants) were satisfied with the assistance, which included help from friends, family and significant others, and sometimes from ACC. Again, participants often found it difficult to articulate suggestions for additional help, but those offered included help from ACC, follow-up care and psychological help and support, as well as more information in general about the injury.

We relied on self-report of symptoms, and found that participants struggled to remember or express help that they received or would have liked. Despite this, the results of our study have significant implications. The information and assistance given to individuals in our study who had suffered a TBI was inconsistent and often insufficient. Older adults in particular were the least happy with the information they received, and expressed a greater

need for psychological input post-TBI. We therefore discuss the implications of our findings in regard to each of our six hypotheses and provide recommendations for patient care following TBI.

Hypothesis 1: Older adults are more likely than younger adults to have experienced memory and cognitive difficulties, negative emotions and/or depressive feelings following mTBI.

We did not find any significant differences between age groups for the number of post-injury symptoms experienced by individuals. Although those in the oldest group reported the fewest problems post-TBI, our results may not accurately reflect symptoms experienced by individuals. For instance, it is possible that older individuals discounted symptoms such as fatigue and difficulties with memory and concentration because they considered that these were due to aging and thus did not report these as post-TBI symptoms. Additionally, we found females reported to experience more symptoms following their mTBI than males.

Few participants explicitly discussed feelings of isolation or depression, but this may be because such feelings were not included in our list of symptoms, so participants had to spontaneously suggest them. However, some participants in the oldest two groups made statements that suggested these feelings. For instance, one 71 year old participant said that the period after mTBI is a “lonely time” and a 51 year old participant said “symptoms can be scary when you’re not expecting them”. Similarly, a 76 year old participant discussed how he would have liked to talk to someone about his problems as he felt that his condition degraded very quickly. Older adults may therefore have benefitted from receiving more detailed information about mTBI after their injury so they were more prepared for symptoms, as well as receiving an offer of psychological help or support. More information and support

following mTBI may therefore prevent patients from developing depressive symptoms or from feeling lonely or scared after their injury.

Hypothesis 2: Older adults will receive less information than younger or middle-aged adults following mTBI

A quarter of all participants did not receive any information following their TBI. In support of our hypothesis, those in the oldest group were most likely to report that they did not receive any information (45% reported no information compared to only 10% of those in the youngest group). Although information about predicted symptoms was the most common type of information received by participants (more than one third of all participants reported receiving information regarding expected symptoms), this was more commonly received by younger adults (42.5%) than older (27.5%).

The limited information received by individuals following a TBI may mean that they are not prepared for symptoms that they experience and have no way of knowing whether they should be concerned about symptoms or when they should seek additional medical input. A lack of information may therefore result in feelings of fear or depression as a result of unexpected symptoms, as previously discussed. It is clear that a large proportion of individuals do not receive information after a mTBI event. But more concerning is that the oldest age group were the least likely to receive information, given that this group has been shown to experience poorer outcomes after mTBI (Forslund et al., 2013; Rapoport & Feinstein, 2000) and be more vulnerable to the effects of the injury (Chua, Ng, Yap & Bok, 2007; Goldstein & Levin, 2001; Senathi-Raja & Ponsford, 2010). Furthermore, without information about precautions to take following their injury, individuals may be at greater risk of second impact syndrome. Second impact syndrome results in further post-TBI

complications, and may cause a long lasting or permanent cognitive disorder, or in the worst case scenario, death (Bey & Ostick, 2009; Guinto & Guinto-Nishimura, 2013).

Verbal information was the second most common type of information received by all participants. However, the usefulness of verbal information following a TBI is questionable. For instance, following mTBI, individuals will often be experiencing memory and concentration difficulties which may impair their ability to remember what they have been told (Guinto & Guinto-Nishimura, 2013). Experiencing cognitive difficulties after mTBI is consistent with PCS (Guinto & Guinto-Nishimura, 2013) and such symptoms should therefore be taken into account when delivering information to patients who have experienced mTBI.

Hypothesis 3: Older adults will receive less support and assistance than younger adults following mTBI.

Contrary to our predictions, we did not find any significant differences between age groups for the type of assistance received by individuals after TBI. Over 70% of participants received additional assistance following their injury and all participants who received additional assistance were satisfied with it. Although the type of assistance provided to participants was varied, it most often came from family, friends or significant others, which suggests a lack of input from agencies such as ACC and a lack of medical, physiotherapeutic and psychological input and assistance. There were however no significant differences between age groups for the types of assistance received, suggesting that a lack of input is consistent across age groups.

The social support offered by friends and family included help with driving and performing daily tasks, as well as emotional support and reassurance. It is possible that help from those in participants' social networks arose out of necessity, due to a lack of input from

other sources. Following mTBI, individuals are likely to need more support than that offered by social networks (Leith, Phillips, & Sample, 2004). However, social support is a very important predictor of recovery so was likely to be useful nonetheless. For instance, effective social support from the patient's family has been found to be significantly related to lower levels of depression following TBI (Rauch & Ferry, 2001). On the contrary, a lack of social support may affect the ability of older adults to return to independent living (Goldstein & Levin, 2010). Additionally, those without a social support system may have greater levels of chronic stress after their injury and therefore demonstrate poorer outcomes, including depressive symptoms (Bay et al., 2009). Those participants who did receive support/assistance from family and other family members noted how they found this beneficial.

However, older adults may have more complex needs following mTBI which are likely to require more support and assistance than can be provided by friends and family alone. For instance, older adults have been found to be particularly vulnerable to the effects of mTBI and may experience poorer outcomes compared to younger and middle aged adults (Thompson, McCormick, & Kagan, 2006; Rapoport & Feinstein, 2000; Rothweiler, Temkin, & Dikmen, 1998). Furthermore, recovery from TBI might be compromised for those individuals who do not have stable support networks or family.

Some participants who did not receive any assistance for their TBI did report receiving assistance for their other injuries, such as additional medical care or help from ACC. Although we excluded such assistance from our analyses, these findings may suggest that where individuals have more physically apparent injuries such as broken limbs, these injuries may overshadow the mTBI and rehabilitation and treatment may be directed at these rather than the mTBI.

Hypothesis 4: Older adults are more likely than younger adults to express dissatisfaction with the information and support/assistance received following their injury

Information received

Overall, we found the majority of participants stated that they were satisfied with the information that they received following their injury. We additionally found some participants (14%) to say that they were happy with the information they received, despite having reported not receiving any. This suggests that a proportion of participants did not feel like they required any information.

The oldest two groups contained the greatest proportion of participants who reported that they were not satisfied with the information they received and the youngest age group (18-35yrs) contained the most people who were happy with the information they received. For instance, of those not happy with the information they received ($n = 9$), 70% were over the age of 50. These results are consistent with our hypothesis, that is, that older adults are more likely to express dissatisfaction with the information they received following their injury. Older adults are therefore not only less likely to receive information after mTBI, but when they do receive information, they are less likely to be satisfied with it compared to younger adults.

Because there were no age-related differences in terms of information received by participants, older adults' lower satisfaction in information received may suggest that either, older adults feel the need for more information post-injury, or, younger adults do not require as much information.

Support/assistance

Contrary to our prediction, all participants who reported to receive additional assistance after the TBI said they were satisfied with this assistance. Although participants did give a number of suggestions regarding assistance they may have found useful, often participants were unable to come up with specific suggestions, despite having expressed dissatisfaction and despite prompts from the researcher. This may have been a result of time elapsed since the TBI or perhaps because participants were unaware of what was available to them.

Additional assistance suggested by participants varied. A need for general information was the most commonly suggested mode of assistance. For instance, participants said they would have liked more information about TBI, expected symptoms and prognosis, as well as information regarding what help was available to them. Such information would have meant less uncertainty surrounded individual's symptoms and recovery.

It is interesting to note that psychological help or counselling was suggested only by participants in the oldest two groups. A total of seven participants (8.75%) made this suggestion, and these participants discussed feelings of isolation and loneliness. It is possible that such feelings may have developed as a result of dealing with unexpected symptoms or having been ill-informed about mTBI and their prognosis. As depressive symptoms are commonly reported after mTBI, feelings such as these should not be ignored. Furthermore, the effect of age is significant, as it is a significant predictor of major depressive disorder (MDD) after TBI (Papa, Mendes & Braga, 2012). Medical professionals therefore need to be aware of the possibility of negative feelings following TBI, particularly in older adults. It would be of great use to provide patients who have suffered from mTBI with an explanation of symptoms to be expected following their injury. Such information would likely minimise

concerns when patients experience difficulties with memory and cognition. Furthermore, it would be useful to provide patients with a number they can call should they become worried, such as a service like Lifeline.

A brief follow up phone call or letter to patients a few weeks after their injury may be also be helpful. For instance, a need for follow-up was suggested by 10% of participants. Participants said they would have liked a follow-up phone call or appointment to check how their recovery was going, and so that they could ask a medical professional any questions about symptoms they may have. A follow-up call would not be costly in terms of resources, while encouraging peace of mind in patients. If it became clear that they patient did need further rehabilitation or support, they could be referred to the appropriate service. However, perhaps if individuals received adequate information about their injury initially, there may be no need for a follow up call as patients would know not to be concerned about their symptoms.

Although assistance from ACC was commonly reported as having been received by participants following their injury (received by 15% of participants), four participants said they would have liked more financial help, and many more expressed frustration in dealing with ACC (10% of participants). As many individuals who have suffered a TBI do not return to work for 1-3 months following their injury (Belanger et al., 2010), financial assistance post-injury may be necessary. Given that problems such as fatigue, irritability and information processing difficulties following a TBI are common (Dean & Sterr, 2013), the recovery process may be less difficult for individuals if the task of gaining assistance from ACC is made easier.

One participant suggested that a support person who acts as an advocate on behalf of the individual may be useful. For instance, this support person could not only assist the

patient with ACC, but also help organise appointments and physiotherapy, help with transport, and assist with anything else the patient may need while they recover. This advocate would act with the patient's best interests in mind and would be there throughout the whole recovery process. Although this suggestion was made by only one participant, we predict many of our participants would have agreed.

6.1 Limitations

Although we only examined individuals who had suffered mTBI, we did not examine the medical records regarding the severity of their symptoms, nor did we examine participant's mechanism of injury. We therefore relied solely on self-report of post-injury symptoms. However, older participants may have experienced difficulty distinguishing between age related symptoms and symptoms as a result of TBI and consequently may have disregarded symptoms such as poor memory and fatigue. Furthermore, in some cases, participants were unable to recall what information they had received following their injury. Although there were no age related differences, it is possible that many of those who did not remember what information they had received had not received any at all.

Less than half of those invited to participate in this study actually participated, which may mean we had a biased sample. For instance, it is possible that some of those individuals who did not take part were more severely affected, and therefore were unable to participate. Furthermore, additional deficits may have become apparent in participants over time but we were unable to evaluate this as we did not perform a follow up survey. However, we did anticipate this, and therefore used a design that ensured equal numbers of participants in each age group. Assuming there was no interaction between injury severity and age, any bias in severity should not have affected the age comparisons that were the primary focus of this study.

The findings of the current study reflect only the support and information offered by the Canterbury District Health Board (CDHB), which operates within the Canterbury region. Those individuals in other parts of New Zealand may have different experiences, and may have received post-TBI care that is superior to that detailed here. However, given the inconsistency in information and support given to patients just within our sample, we predict that further inconsistencies would be apparent within other Emergency Departments.

6.2 Future research

Overall, participants in our study received limited information following their mTBI and provided varied suggestions as to ways in which information or assistance could have been improved. However, further investigations may be necessary to determine whether there are any age-related differences in terms of patient needs after an mTBI event, especially given the evidence of poorer outcomes in older adults following a TBI. Additional research may also be necessary in order to develop resources that suit the needs of older adults and that ensure these individuals are well informed following a TBI. Such research will be useful given the increasingly aging population and the high incidence of mTBI in older adults.

7. Conclusions and recommendations

It is clear that those who suffer from a TBI do not feel that they receive sufficient information or support following their injury, or they do not recall what information they received. Very few participants in our study recalled receiving written information and many did not recall receiving any information at all. Older adults were less likely to receive information after their injury, and those who did receive information were less satisfied with it than younger adults. As a result, participants reported a lack of information about symptoms they should expect or be concerned about, how long until they would be fully recovered or what precautions they should take during the recovery process. Furthermore, a

portion of participants found it difficult to access insurance entitlements to assist recovery, stating that they spent a long time waiting for action and that they found trying to gain compensation frustrating. Other participants reported feeling that they were alone and feeling scared due to their perceived worsening state. Based on our findings, the experiences of individuals after mTBI regarding information and rehabilitative support and assistance are not overly positive, and given the high incidence of mTBI and the associated economic and health-related costs, action may need to be taken to remedy this for future patients.

Recommendations

The results from this study suggest that a more consistent approach should be applied to post-TBI care. We suggest that every patient who attends ED or is admitted to hospital with a mTBI receives comprehensive written information explaining what a TBI is, what symptoms the patient should expect and how recovery will pan out. Additionally, all patients with a mTBI should be provided with a contact number that they can call should they have any questions or should receive a follow up letter or phone call with the opportunity to ask questions. Finally, individuals who have suffered a TBI should receive some basic guidelines about gaining assistance from ACC. Such information would ensure that all patients are well informed and that they have written information that they can keep and refer back to at a later date if necessary. Although we did not analyse whether those who received more information reported better recovery, we have based the above suggestions on participant's statements about their post-TBI experiences and analysis of information and assistance they would have liked to receive.

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Appendix

Appendix A: Consent Form.

I have been invited to take part in the *study Incidence, prevalence and rehabilitative input for older people experiencing traumatic brain injury*. I have read the information letter that has been provided on the aims and purpose of the study and I have read and understood the information it contained. I have been given an opportunity to discuss the study and I am satisfied with the answers that have been given. I have had sufficient time to consider whether to take part.

I understand that:

- Participation in this study is voluntary (my choice)
- I am free to withdraw from the study at any time and this will in no way affect my future healthcare
- I am free to refuse to answer any questions that I do not want to answer
- This study has approval from the Upper South A Regional Ethics Committee
- My participation in the study is confidential and no information that could identify me will be used in any reports that may be generated from this study.

I _____ (insert full name) hereby consent/do not consent to take part in this study, entitled "*Incidence, prevalence and rehabilitative input for older people experiencing traumatic brain injury*".

I am free to be contacted at the following time: _____

Appendix B: Questionnaire used in phone interview

1. Thinking about the time you had your head injury, what information were you given?
2. After your head injury, did you experience any problems?
3. Following your head injury did you experience any of the following?

Problems remembering?

Problems concentrating?

Fatigue?

Irritability?

Sensitivity (loud noises, light, etc.)

Difficulties with movement?

Difficulties thinking?

4. Did any of the above problems pre-date the injury?
5. Were you happy with information you received following your injury? If so, what information did you receive, and who by?
6. Would any other information have been useful to you?
7. Did you receive any other assistance (e.g. family, friends, ACC)
8. Did you find this assistance helpful?
9. Would any other type of assistance have been helpful?

Appendix C: Letter inviting participation

Dear

Christchurch hospital outpatient records indicate that you experienced an injury to the head on (date).....

Dr Martin Than (Emergency Department Christchurch Hospital) and Dr Audrey McKinlay (University of Canterbury) would like to invite you to participate in some new research examining what type of information and or assistance that people receive after they have an injury to the head.

We are conducting the research by phone interview which will take about 5-10 minutes to complete. Over the next few weeks our Masters student Olivia Taylor will contact you to see if you would like to take part.

As part of the telephone interview we would like to ask whether you experienced any problems and what type of services you received following your head injury. If you did receive input from outside agencies we would also like to know whether you were satisfied with these services and what other input would have been useful. We have enclosed a copy of the questions that we would like to ask you along with this letter of invitation.

Participation in the research is entirely voluntary. You do not have to answer all the questions and you are free to withdraw at any stage. If you choose not to take part in the study you do not need to give a reason and it will not affect your health care or treatment. We have enclosed a copy of the consent form in this letter.

All the information provided for this study will be treated in the utmost confidence. All personal information will be securely stored, accessible only by the principal investigators of this study. Your identity will not be disclosed in any reports based on information from this study.

If you agree to participate Olivia (Masters Student at the University of Canterbury) will phone you at a time that is convenient for you.

This study has been given approval by the Upper South A Regional Ethics committee. If you have any questions about this study please feel free to contact Dr Audrey McKinlay at the University of Canterbury (telephone number 364 2987 ext. 7885).

Yours Sincerely

Dr Martin Than,

Emergency Department

Christchurch Hospital